Epidermolysis bullosa and the need for innovative care

Dear Sir,

Epidermolysis bullosa (EB) is a genetically determined skin condition in which skin and mucosa blister and break down in response to minimal everyday friction and trauma. In its mildest form, blistering on the feet impairs mobility; severe forms result in increasing disability or death in early infancy. Many children develop large wounds which are notoriously difficult to heal, and when healing is achieved, trauma causes rapid breakdown.

This is a painful and debilitating condition and my team strives to find innovative treatments to improve the quality of life for patients. We have, on occasions been encouraged to treat the wounds as if they resulted from a burn, and it has been suggested non-healing results from a failure to use topical antiseptic solutions. I dearly wish such measures would resolve the problems of skin deficient in essential supportive structures and vital proteins, but we can only offer our best practice while research continues towards gene therapy.

Controversial to the theory of moist wound healing, we frequently find this practice increases the rate of blistering. This is echoed in the routine of regular bathing, which is often impossible due to the extent of ulceration, the lack of intact skin to facilitate handling, and the pain from exposure of all the wounds, despite maximum analgesia.

Our management is to lance blisters (a principle contraindicated in many other conditions) in order to prevent their rapid enlargement. We apply cornflour to dry the blistered areas and reduce friction. Where is our evidence base for this practice? I can only state in our defence that we have been using this method for over 10 years and have no ill effects to report. Unlike talcum powder, cornflour is chemically inert, an excess of 10 years and have no ill effects to report. Unlike talcum powder, cornflour is chemically inert, does not dissolve in contact with fluid and will not cause irritation should it come in contact with mucous membranes.

Wound management is complex and specific to the type of EB. We often find it necessary to use dressing combinations in order to promote wound healing without the risk of tearing intact skin. Dressing combinations are costly and I believe should only be used when strictly necessary, in this case to avoid risking extensive damage, pain and resulting loss of patient and carer confidence.

From experience we know when we use a specific dressing to reduce the bioburden or to control exudate or odour, such dressings adhere to the wound bed and tear the surrounding skin on removal. In order to protect against this we apply the dressing in combination with one proven to be pain and trauma free on removal.

Patients are often reluctant to try new dressings when they have previously experienced pain and trauma following removal of an unsuitable dressing. They have confidence in trying new dressings over a dressing proven to be non-adherent on their skin.

I am aware many of my ideas may be considered untoward and even outside the boundaries of the Medical Devices Act, but faced with a child suffering from a relentless condition, which causes constant pain and, in its severe forms, progressive disability and premature death, I feel driven to search out treatments to minimise symptoms, while ensuring patient safety is paramount.

Jacqueline Denyer, Clinical Nurse Specialist, Epidermolysis Bullosa (Paediatric)

The evolution of a tissue viability service in a mental health trust

Dear Sir,

I am writing in response to your editorial in the May edition of Wounds UK (Gray, 2005; Wounds UK 1(2): 6) regarding management awareness of the importance of an active tissue viability service.

For the last six years, the mental health trust I work for has supported me in the development of a tissue viability service in our older person’s directorate. This has led to evidence-based care, greater satisfaction for staff and increased morale as a result. Within the first year, I had eradicated the APAM rental bill from £25k by introducing a risk-assessed and needs-led database to monitor the issue and return of equipment, devised tailored training programmes for both qualified and unqualified staff, established a link nurse system, and provided all areas with a wound care resource pack.

Other developments included the introduction of compression bandaging, a wound care formulary to help rationalise prescribing and reduce waste, pressure-reducing mattresses and cushions as standard on all wards, and a mattress-maintenance programme. As with any initiative, other directorates within mental health began to contact me for advice/visits/training.

Making wound care education meaningful

Dear Sir,

Wound care education is something we are all involved in at one level or another. This may be part of an organised course, the instruction of colleagues in wound assessment techniques, or giving explanations of wound management products to patients or their carers.

Wound management is an ever developing and changing field, yet there are few agreed standards as to how this information is passed on to practitioners or to health service users. One of the key issues with wound management education is keeping pace with technology. Another is ensuring that those who need to know, get to know. Much of the training, unless part of an organised course, will be ad hoc and in many cases, we rely on study days and study sessions to provide practitioners with new knowledge, yet how effective is this approach?
This style of session may be delivered as a group of presentations with little opportunity for interaction or debate and, in essence, there is no way of determining learning from the students’ perspective. It is also worthwhile remembering that students will learn differently and it is difficult to find a one size fits all approach.

The traditional approach to teaching does have a place. It is often a case of simple economics; however, it would be much more meaningful to students if they actually have a chance to get involved in and to learn from the session.

Nurses now need to have more than just knowledge. In order to function at the high levels that we require, nurses should be able to problem solve, critically reflect on practice and demonstrate sound clinical decision making ability.

This level of learning cannot be achieved by simply attending presentations. There is a need for wound management education to reflect this need, to allow the student to get involved, to reflect on past experience and apply this to new situations in order to move on.

For many of us involved in wound management education, the use of case studies have proved a beneficial adjunct to assist in examining the true context of wound management. Staff and students can relate to the concrete experience of patient episodes as they create a more realistic, more meaningful learning experience. This must of course be coupled with available research and the related theory.

In our wound assessment module last year we opted to deliver the material in a blended approach. This allowed some time to be devoted to theory delivery and also time to be devoted to case studies and problem-based learning scenarios which would reflect similar issues to those which the students would face in practice. The assessment was also changed from an essay to an open book examination. This allowed the students to practice problem solving under examination conditions with books and articles to support their findings. The feedback from the students was mixed; however, the general consensus was that they felt they had benefitted greatly from having to study all the course material for the examination and that it was clinically relevant.

This was an excellent outcome for the lecturers, as we felt that in teaching wound assessment, it would be wrong to produce students who had only studied part of the course material, which may have occurred if an essay had been used. This year we will include more formative work throughout the module in order to ease nerves and to help exam technique. This will also encourage more evaluation from the students as the course progresses allowing us to adjust material as we go.

To conclude, it is essential that we strive to achieve high standards in wound management practice through similar high standards in wound management education. We must always consider the aims of the teaching, what we are trying to achieve and how this can best be done. If time permits, then we should seek to evaluate the session in order to gauge the students’ learning.

John Timmons, Lecturer in Nursing, Glasgow
Caledonian University, Glasgow

A holistic approach to living with a leg or foot ulcer: the socio-psychological benefits of effective personal hygiene

Dear Sir,

With regard to the excellent content on various approaches to wound care, I note that most articles are concerned with the direct treatment regime whereas the areas of psychological trauma and health-related quality-of-life (HRQoL) have little coverage. While I appreciate that non-drug-based innovations are few and far between, there is a new device, recently approved on all UK drug tariffs for issue on FP10/GP10 by both nurses and GPs that would be of very significant and direct benefit to virtually every patient with a chronic leg wound.

The Seal-Tight Wound Protector achieves the hitherto impossible, allowing patients to bath or shower with all dressings in situ yet ensuring these dressings remain dry. This device is inspirationally simple and can be applied directly by the vast majority of patients unaided yet it is 100% effective and applies no pressure at all to the affected area.

The Prescription Pricing Authority created a precedent when HRQoL was accepted as a valid criterion for acceptance for Seal-Tight. Submitted test results that were gathered using the Cardiff Wound Index Schedule showed a clear and very significant increase in the scores between two groups, the control group having no access to Seal-Tight, the other being patients that used the device.

It was also discovered that for all patients that got their dressings wet while trying to wash and informed their nurse in order to have them replaced, a slightly greater number chose not to report the matter leading to potential issues of infection and osmotic shock to patients’ wounds.

This is a rare case of all round win/win where the patients have an important aspect of their lifestyle restored, the clinicians no longer have unscheduled changes of dressings with which to contend and the trust ‘spend’ actually reduces.

David Watt, Managing Editor, Autonomed Ltd